

# Agenda Item 8

		<b>THE HEALTH SCRUTINY COMMITTEE FOR LINCOLNSHIRE</b>	
Boston Borough Council	East Lindsey District Council	City of Lincoln Council	Lincolnshire County Council
North Kesteven District Council	South Holland District Council	South Kesteven District Council	West Lindsey District Council

Open Report on behalf of Lincolnshire Sustainability and Transformation Partnership

Report to	<b>Health Scrutiny Committee for Lincolnshire</b>
Date:	<b>14 November 2018</b>
Subject:	<b>Delivery of the NHS England National Cancer Strategy in Lincolnshire</b>

## Summary

This report advises the Committee of the progress of the delivery of the *NHS England National Cancer Strategy* across Lincolnshire. As part the Lincolnshire Sustainability and Transformation Partnership, we have been working to implement a cancer improvement plan that will deliver the priorities in the national strategy for the Lincolnshire population.

This report outlines our current work programme and the future priorities that will support improved outcomes for people living in Lincolnshire.

## Action Required:

The Health Scrutiny Committee is invited to note the progress on the delivery of the NHS England National Cancer strategy across Lincolnshire.

## 1. Introduction

Receiving a cancer diagnosis is a life changing event. The NHS England National Cancer Strategy '*Achieving World-Class Cancer Outcomes*' was published in 2015 by the Independent Cancer Taskforce. The key strategic priorities of this strategy are to:

- Radically upgrade prevention and public health
- Lead a national drive for earlier and faster diagnosis

- Put patient experience on a par with clinical effectiveness and safety
- Transform our approach to living with and beyond cancer
- Invest in high quality modern service
- Transform commissioning, provision and accountability.

In Lincolnshire, as part of our Sustainability and Transformation Partnership, we have been working to implement a cancer improvement plan that will deliver these strategy priorities for the Lincolnshire population. This report outlines our current work programme and the future priorities that will support improved outcomes for people living in Lincolnshire.

## 1.1 The Starting Point

In January 2017 we held the first ever Lincolnshire Cancer Summit. This brought colleagues from across the Lincolnshire health and care system together with colleagues from the East Midlands Cancer Alliance, patients and members of the public together to consider a Case for Change. The case for change presented all the available data and information together in one place to provide 'a single version of the truth', allowing everyone to work from the same understanding and evidence base. It introduces the changes that are needed, the benefits that the changes can bring.

Together colleagues at the summit identified areas of successes, areas of challenge and national best practice. This provided the basis from which we have been able to develop a plan to support the transformation of the cancer care system so that it is responsive to local needs, meets mandatory care standards and creates excellent health and wellbeing outcomes for our local population.

A summary of the information considered is set out below:

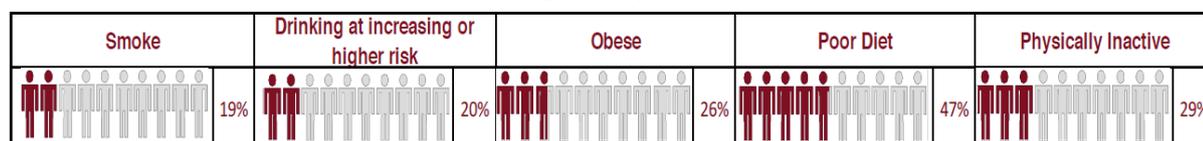
- Cancer is a major cause of premature mortality accounting for more than 1-in-4 of all deaths and between 2012 and 2014, rates due to cancer were higher in Lincolnshire than the national level
- Cancer prevalence across the 4 CCGs ranges from 2.7% to 3.2% (national average = 2.6%) and in 2016/17 there were 25,599 people living with Cancer in Lincolnshire
- The most common cancers are Breast, Lung, Colorectal and Prostate and of these, colorectal is the most common cancer in Lincolnshire
- Smoking prevalence in adults is 21% (2016) which is higher than the England total of 15.5%
- 65% of adults are classed as overweight (2015/16), above the England total of 61%
- People diagnosed with cancer via an emergency route is higher in Lincolnshire than other areas
- Screening programmes are well attended across Lincolnshire, all above the national average.
- There are three Cancers that have Screening programmes currently and include Colorectal, Breast and Cervical.

### The Cancer Health Outcome and Inequality Gap

- Life expectancy at birth: the average number of years a male, in Lincolnshire, would expect to live is 77.6 which is below England which is 79.5 and the world leading nation which is Switzerland at 81.3 years. Based on 2013/15 data

- Life expectancy at birth: the average number of years a female, in Lincolnshire, would expect to live is 81.9 which are below England which is 83.1 and the world leading nation which is Japan at 86.8 years .Based on 2013/15 data
- The One year survival (all cancers) for patients diagnosed in 2015 in Lincolnshire (STP) was 71.4%. This was below the England total at 72.3%. This ranged from 70.7% in Lincolnshire East and West to 72.5% in South Lincolnshire
- Whilst survival rates for people diagnosed with cancer have improved, the difference between survival rates for the more survivable cancers and the less survival cancers is significant at 55%. Less survivable cancers account for almost 50% of all deaths from common cancers (see table 2 below)
- All cancers combined are the most common cause of death in the UK, accounting for more than a quarter (28%) all deaths (2016).
- In males in the UK, all cancers combined are the most common cause of death in the UK as a whole (30% of all male deaths). In females in the UK all cancers combined are the most common cause of death in the UK as a whole (26% of all female deaths).
- 53% of deaths for all cancers combined in the UK are in males, and 47% are in females. This reflects the sex differences in cancer incidence (higher in men than women) and survival (higher in women than men).
- For all cancers, the percentage of patients diagnosed at stage 1 & 2 (excluding unknown stages) in Lincolnshire STP was 53.6%. This was slightly below the England total which was 53.7%
- There is wide variations in access to care and treatments across Lincolnshire and across the East Midlands
- The East Midlands and Lincolnshire specifically has relatively low levels of involvement in research trials compared to other parts of the country.

Prevalence in the East Midlands of key lifestyle factors (table 1)



Graph showing cancer 5-year survival in 2015 between 1971 and 2015 (table 2)

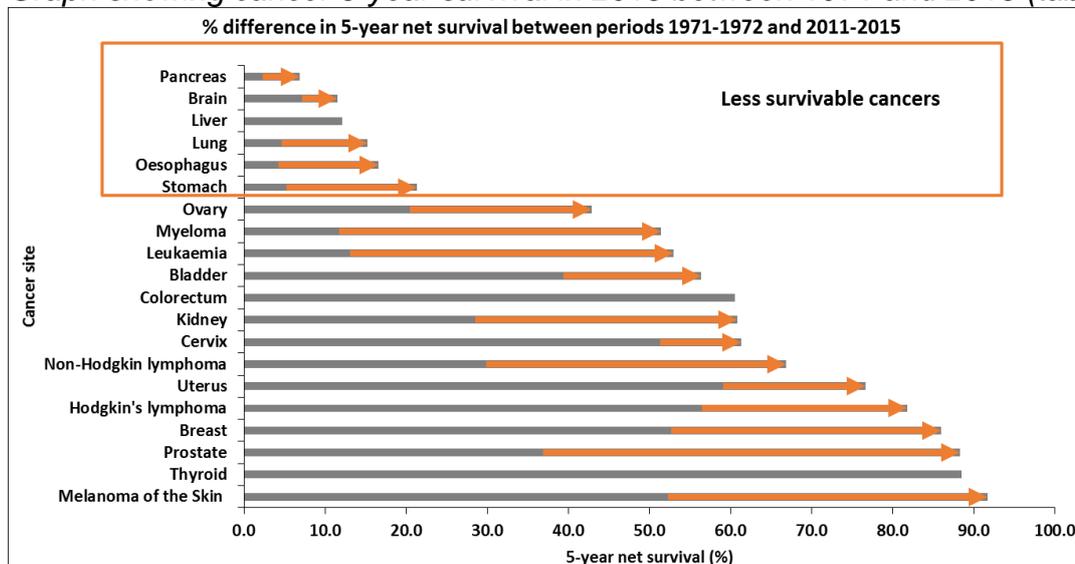


Table 2: Cancer Five Year Survival in 20 common cancers. Graph showing: cancer five-year survival in 2015 (grey bars) in England. Orange arrows highlight the difference in five-year survival between 1971 and 2015.

Data compiled from Quaresma et al, 2014, the Lancet (1971-2001) and ONS (2011-1015). Note that there is no historical data for liver, colorectal and thyroid cancer.

## **1.2. Current investment in Cancer Services**

Four in ten cancers could be prevented by supporting people with lifestyle changes such as not smoking and maintaining a healthy weight, yet the focus and resources continue to be on treatment and follow-up.

It is estimated that currently over 80% of health spend is in the hospital setting and only 12% within the community and even less on prevention.

Many people present late with their cancer symptoms, leading to poorer outcomes and resulting in higher costs and as such the system needs to understand why this is happening.

Lincolnshire has a higher than average late diagnosis figures. One of the key priorities of the Lincolnshire plan is to raise awareness and improve clinical pathways to ensure that patients presenting with vague symptoms are referred promptly and that the diagnostic pathway within secondary care is streamlined to support timely diagnosis. Cancer Research UK actively work with partners across Lincolnshire by raising awareness in Primary care of the importance of recognising the early signs and symptoms of cancer.

A key area of focus during the last twelve months has been to establish faster diagnosis pathways. A number of specialist teams now offer straight to diagnostic test to enable a faster route to diagnosis. United Lincolnshire Hospitals NHS Trust (ULHT) have provided primary care with referral forms that allow the GP to directly refer patients into a diagnostic test these include Breast, Lower Gastro-Intestinal, Upper Gastro-Intestinal, Prostate and Lung this ultimately reduces the number of days a patient is on a pathway with the anticipation that a diagnosis will be identified sooner.

People should be cared for in the right place, at the right time and by the right person. More cancer care could be delivered in the community, 'closer to home'.

## **1.3 Patient Experience**

Quality of cancer care is inconsistent, despite the best efforts of staff and in Lincolnshire there are longstanding issues with meeting NHS Constitutional Standards. Lincolnshire was rated amongst the lowest by patients who responded to the National Cancer Patient Survey in 2016.

## **2. Priorities Developed and Agreed at the Lincolnshire Cancer Summit**

Whilst everyone who attended the cancer summit agreed there was much to do the following priorities were agreed :

- Improve delivery of the 62 day constitutional standard
- Improve patient experience
- Improve service in the community for people living with and beyond cancer

### **2.1 Improve Delivery of the 62 day Constitutional Standard**

*The 62 day treatment standard is a national target included as part of the NHS Constitution. The aim is that a patient should receive their first treatment no later than 62 days from the date that their GP made the initial referral for investigation of symptoms that may suggest a cancer diagnosis. This standard is important because the best outcome for patients are achieved the earlier treatment is commenced. The national standard is that 85% of patients should receive their first treatment within 62 days.*

Whilst some tumour sites perform consistently well against the 62 Day standard: Skin & Breast and there has been increased reliability across all cancer pathways in relation to Chemotherapy and Radiotherapy delivery.

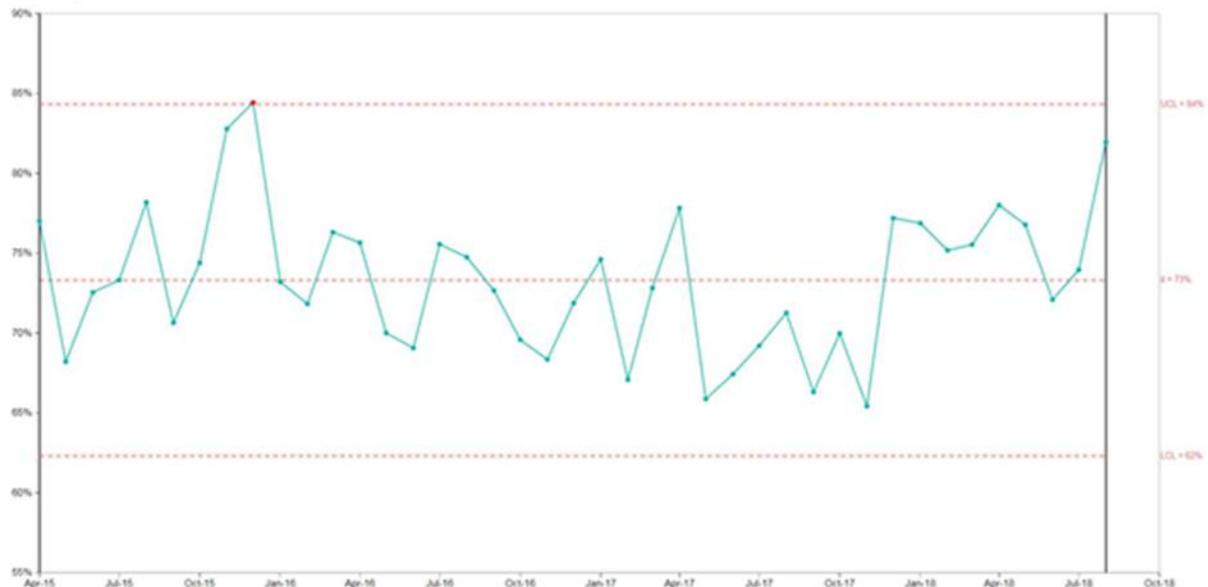
Colleagues from across Lincolnshire have come together to focus on the clinical pathway and support transformational change for specific tumour sites including Urology/ Upper Gastro-Intestinal/ Colorectal/ Lung and Breast, more recently Head and Neck and Oncology, where it was none that there was a challenge achieving the 62 day standard.

The methodical approach enabled us to see what was happening at each key point in a patient's journey and where there were delays, which by changing the way we worked we could eradicate or remove. The following are examples of changes that have been made:

- All patients contacted by ULHT to book an appointment to review symptoms that may suggest a cancer are asked whether they understand that they have been referred by their GP on a two week wait pathway.
- Where possible patients are offered choice for their first appointment within seven days of their referral. This enables patients to ask for slightly longer if they want to arrange for someone to come with them but still ensures they are seen within two weeks.
- Nurse triage and straight to test appointments have been introduced for patients with suspected colorectal cancer. This means that when the patient first sees the Consultant the Consultant has access to their results.
- Primary and secondary care clinicians have come together to review and standardise clinical referral forms, the tests they use for diagnosis and implement timed pathways that are in line with the best in the country.
- The Lincolnshire system has invested in new systems and additional resources to ensure that it is possible to track exactly where a patient is on their pathway and to expedite any potential delays.
- Understanding the demand data and patients flows has been integral to the improvements made to the 62 day performance, gaining visibility of the patient numbers referred into or out of county allows the system to provide the capacity to

meet the demand. The system clearly understands the numbers referred into ULHT and the numbers referred to other providers. Both the trust and Commissioners have worked on this together to ensure clarity around each pathway. On average about 80% of Lincolnshire patients flow into ULHT and 20 % flow out of county to other providers that are closer to where they live.

*Graph below shows 62 day performance for all specialities at ULHT, the graph indicates a step change in improvement from January 2018 where performance has been maintained over 75% bar June and July peaking in August at 82%. The last time performance achieved over 80% was in 2015.*



In addition to the changes we have made we understand that there is further work to do. This work will include working with other trusts to reduce delays associated to:

- Referrals to tertiary cancer centres for onward treatment,
- Diagnostic/pathology delays,
- Specialised CT /staffing levels
- Availability of High Dependency Unit/Intensive Care Unit beds
- Outpatient appointments not attended as planned ('Did Not Attends')
- Use of outdated follow-up models (which means appointments are available for new patients)
- Vacancies in key positions: e.g. consultants, GPs radiologists, radiographers, pathologists, cancer nurse specialists, endoscopists, community nurses and many more.
- Use of technology , such as skype and telehealth which could support reduced patient travel

## **2.2 Review of Patients who had to wait more than 104 days for their Initial Treatment**

Although waiting time performance is below average, Lincolnshire is keen to ensure that outcomes remain good for patients. For all patients that have had to wait more than

104 days for their initial treatment a clinical review is completed to determine whether the patient has suffered serious or moderate harm as defined by NHS England.

In April 2018 an independent audit of the trust's review was arranged. The purpose of the audit was to ensure that the processes used by the Trust are robust. Professor Steve Ryder, Deputy Medical Director of the East Midland Cancer Alliance, visited to audit the review of twelve patients who had waited over 104 days.

Key Findings of the independent audit were:

1. No patients suffered serious or moderate harm as defined by NHS England criteria
2. The review agreed with the assessment of the ULHT team as to the root cause of the breach in 62 day pathway with only two minor amendments, for example the potential role of capacity versus patient choice.
3. Five breaches appear to be primarily the responsibility of a tertiary provider with referral being made from ULHT at an appropriately timely place in the pathway (between 18 and 25 days). The remainder sit with ULHT.

### **2.3 Patient Experience**

We have been supported by patients, support groups and health watch to understand how we could improve patient and family experience of their cancer treatments.

Over the last year there have been changes to the way we communicate with and support patients and their families. Some specific changes have included:

- Asking patients whether they understand that they have been referred on a cancer pathway when initial appointments are made
- Arranging for someone to contact them if they hadn't understood this and require additional support
- Reviewing how Clinical Nurse Specialists work with patients
- Identifying patients who are not attending appointments, making their GP aware so that they can provide additional support

Every year there is a national cancer experience survey. Over the last twelve months there has been an improved overall score of 0.3 to 8.6/10. Whilst this is still below the national average is 8.8/10 we understand from the comments and directly from patients and their families that they want to be more involved and active in their care, and that they would like more support to feel confident to be able to self-manage after treatment.

### **2.4 Living With and Beyond Cancer**

Until recently the focus for cancer services has been on providing a prompt diagnosis and treatment for the cancer, but there are currently 2.5 million people in the UK living with cancer; this is expected to rise to 4 million by 2030, with 45,400 living in Lincolnshire alone. Cancer survival is at its highest ever, with improvements made in the last 15 years, and

people are now twice as likely to survive at least 10 years after being diagnosed with cancer as they were at the start of the 1970s.<sup>1</sup>

It is known that people who are offered good support before, during and after a cancer diagnosis and treatment often have better outcomes than people who are not. In Lincolnshire, the support that people can get is patchy and services are sometimes disjointed. The programme aims to change this.

In 2016 Lincolnshire West CCG, as lead for cancer in the county, secured substantial funding to develop the Lincolnshire Living with and Beyond Cancer Programme (now re-named the Lincolnshire Living with Cancer Programme) from Macmillan Cancer Support.

The programme aims to transform the way we support people living with cancer. The aim is to ensure there are seamless integrated pathways of care across all care sectors, and to particularly address the current unmet holistic needs reported post treatment. The aim is to transform services to fully support people throughout each phase of illness: from the period between referral and a cancer diagnosis, and through diagnosis and into treatment; improve support for people in their transition from acute care back into primary care and into recovery and survivorship; and for people with advanced disease, support people in their transition from acute care into palliative and end of life care.

Our work has involved speaking directly to patients – below are some of their stories

***"Cancer is life-changing and it doesn't stop when the treatment ends. This needs to be better recognised locally in our cancer support pathways."***

***"I have found the mental side of cancer the hardest to overcome. It changes you completely and makes you question and re-evaluate your whole life. I have struggled with a lack of confidence and it has taken a lot of time for me to accept that I will be never be the same person I was before."***

***"My husband passed away last April, 1 month after being diagnosed. Since the initial diagnosis he had no quality of life as he was too ill to receive any chemo etc. Although it is now 10 months since he passed I still feel in a state of shock about the speed of everything happening. Obviously all the nurses and doctors etc. were concentrating on him, rightfully so, but I feel once I lost him, I was offered no support and I have even been told I don't qualify for counselling as I am 'just' going through bereavement. So in answer to the question, nothing has 'allowed' either of us to get the most out of life. My husband's life is no more at the age of 55 and I am struggling to have a life without him."***

During the last 18 months we have:

- Engaged with 400 healthcare professional, patients, carers and significant others from around the county were asked: what kind of support already exists and what kinds of support are missing? A wide range of information, experiences and stories were gathered, and from these were extracted the kind of support patients would like

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<sup>1</sup> Cancer: Then and Now. Diagnosis, treatment and aftercare from 1970 – 2016. Macmillan Cancer Support August 2016.

to receive, what the experience should be like and the changes they would like made.

- Developed a strategy to support patients affected by cancer in Lincolnshire across the whole system, using a collaborative approach with partners from across Lincolnshire. Included were all 4 CCGs, Lincolnshire County Council Public Health, our providers – ULHT, Lincolnshire Community Health Services NHS Trust and Lincolnshire Partnership NHS Foundation Trust, Healthwatch Lincolnshire, Macmillan, Cancer Research UK, University of Lincoln, Patient and Public Involvement groups, Every-one and St Barnabas Hospice.
- Agreed that our aim is “To develop person-centred, local support for people living with and beyond cancer, their carers and significant others in Lincolnshire”.
- Agreed the following priorities:
  - **Your information** – people get very fed up with having to give their information time and time again, so looking at ways to stop this happening.
  - **Pathways** – map the way people move through their diagnosis and treatment, and what happens after treatment, aim to make the processes smoother, and also put in support so that people don't miss appointments.
  - **Joining things up** – sometimes different services do not work together very well, so work with other programmes to ensure that everyone works together more readily. They've told us that sometimes organisations don't communicate very well between themselves either.
  - **Workforce** – make sure workforce supported during this programme. Look at volunteer and peer support services, and how they can be involved.
  - **Communication and conversations** – people have said that sometimes the communication between professionals and themselves could be clearer.
  - **Information, advice and support** – many people have said that they do not know what's out there to support them, and don't know where to go to get information, advice and support. Exploring ways that everyone (and this includes health and social care professionals) know where to go for what they need.
  - **Support services** – there are support services in Lincolnshire, but there are gaps. Explore ways to use the services we already have, make them stronger and start new services to help fill the gaps. Many people have said that the psychological and emotional impact of cancer is not well recognised, and more could be done to support this.
  - **Equity across Lincolnshire** – where you live can have an impact on the support you get. Explore ways in which people in all parts of the county can access support more easily.

- Developed a programme framework was developed to build work-streams, projects and enabler work-streams. This programme will link with the neighbourhood working framework being developed through the Integrated Community Care programme.
- Appointed a team to deliver the programme :
  - The current team are all currently funded externally by Macmillan cancer Support, and work closely with a wider team employed by Lincolnshire West CCG and ULHT.

<b>LWC Programme Manager LWCCG</b>		
<b>Acute Project</b>	<b>Community Project</b>	<b>IA&amp;S Project</b>
Macmillan Lead Cancer Nurse ULHT	LWC Programme Manager LWCCG	Macmillan Lead Cancer Nurse ULHT
Acute Facilitator(s) ULHT	Community Facilitators LWCCG	Acute Project Manager ULHT Community Project Manager LWCCG (TBC)

Our Local Workforce Action Board programme is working to:

- Ensure all cancer patients have access to a holistic needs assessment, treatment summary, cancer care review, and a patient education and support event which comprise The Recovery Package<sup>2</sup>
- Develop and commission risk stratified pathways of post treatment management;
- Promote physical activity;
- Understand and commission for improved management of the consequences of treatment.

The three projects are concentrating on rolling out the four elements of the Recovery Package in secondary care (Holistic Needs Assessments and Treatment Summaries) and the community (Cancer Care Reviews in primary care – currently usually carried out by a GP, and access to Health & Wellbeing), and enhancing the existing Macmillan Cancer Information and Support Service (MCISS) to be the conduit by which we support people at the end of treatment to access all the services in their community which can help them self-manage and continue to enjoy life; albeit their new life.

To test different aspects of the Recovery Package in different areas ‘Macmillan Community Facilitators’ are running test projects in Gainsborough, Boston, Grantham, Lincoln and Spalding looking at ‘navigation’ and access to existing services such as the Macmillan Direct Volunteering Service, Social Prescribing, The Wellbeing Service and Healthy Lifestyle services. They are also working with GP practices and patients county-wide to understand what is currently happening around Cancer Care Reviews.

Results of these test projects will be available in November and these will inform the next part of the programme.

<sup>2</sup> <http://www.macmillan.org.uk/about-us/health-professionals/programmes-and-services/recovery-package>

In the meantime, a substantial further bid to Macmillan is being prepared, to greatly enhance the current MCISS, to help more people access the information and support they need.

#### **2.4.1 The Breast Pathway**

The focus has been on one pathway to give a sense of what the current experience is like for people who have breast cancer. The pathway has been mapped and details of patient numbers have been gathered and analysed. The aim is to understand the number of people starting and finishing their treatment in ULHT and also out of county trusts – Peterborough, Kings Lynn, Nottingham and Grimsby. It has been difficult to extrapolate the data sets from the pathway due to varying systems that are not aligned or link to each other. This approach to understand the data has been a collaborative in order understanding the current state.

#### **2.4.2 Macmillan GPs**

Further funding from Macmillan has been secured to recruit 4 Macmillan GPs in the county. These GPs will not be directly working with patients; rather they will be working with their peers, and also supporting different aspects of the whole Cancer Improvement Programme, and palliative and end of life services. It is expected that the GPs will be in place in the New Year.

#### **2.4.3 Co-production**

Co-production is different from engagement with patients, in that it gives people with lived experience the opportunity to shape and influence how services and projects are designed and delivered. It is one of the fundamental principles of our programme, and is an element of work by which we will be measuring our success. External funding from Macmillan is being sourced to develop and establish a Living with Cancer Co-production Group of 8 – 15 people affected by cancer. Experts in this emerging field in the county will be involved to do this effectively, and it is believed that this is the first LWC programme in England to do this.

#### **2.4.4 Evaluation**

The Outcomes Framework, which was developed as part of the Strategy development, will be used to self-assess successful outcomes. However, to fully evaluate the programme and projects, Lincolnshire has been chosen by Macmillan as one of four areas in England to measure the impact of the Recovery Package. This is likely to be carried out by an academic or research group and it is anticipated that this will go out to tender in the New Year so that the second year of acute and community projects can be evaluated.

### **3 Future Plans**

Improving cancer services remains a local and national priority. The Lincolnshire Cancer Team is continuing to work with key partners to deliver changes that bring about real benefits for patients that are affordable and sustainable. Our collective focus remains on developing person-centred cancer services for people living in Lincolnshire and ‘making the right things happen’

We are currently refreshing our plan and working to finalise the key priorities for the coming year. These will include:

- Achieving and sustaining the 62 day treatment standard
- Working with partners from the East Midlands Cancer Alliance and Lincoln University to develop arrangements to address workforce gaps.
- Work with partners to develop service delivery models that will support fragile services and reduce the need for patients to travel out of county.
- Build on our experience of working with partners to establish services in Lincolnshire that we cannot currently support for example for some diagnostic tests patients have to travel to other counties
- Continue to implement the Living with and beyond cancer plan – with specific focus on securing additional funding to develop the Macmillan advice and support service.
- Roll out of community based follow up services.
- Working with Cancer UK to understand what needs to happen to improve early diagnostic rates and agree a work plan to address identified gaps.
- Raise awareness of the fact that lifestyle changes can reduce the risk of getting cancer – that is some cancers really are preventable.

#### **4. Conclusion**

The Committee is invited to consider the progress with the local delivery of the NHS England National Cancer strategy.

#### **5. Consultation**

This is not a consultation item.

#### **6. Background Papers**

No background papers within Section 100D of the Local Government Act 1972 were used in the preparation of this report.

This report was written by Sarah-Jane Mills, Chief Operating Officer, Lincolnshire West Clinical Commissioning Group on behalf of the Lincolnshire Sustainability and Transformation Partnership ([Sarah-Jane.Mills@lincolnshirewestccg.nhs.uk](mailto:Sarah-Jane.Mills@lincolnshirewestccg.nhs.uk))